The EHE Foundation (USA)
The EHE Rare Cancer Charity (UK)
The EHE Rare Cancer Foundation (Australia)
EHE Italia-Associazione Non Solo Laura ODV
EHE Canada

Quarterly Newsletter for the EHE Group
January - March 2024

the pledge

Edition 36

Contents

Front cover:

Dr Silvia Stacchiotti leads participants, under the auspices of EORTC, attending the soft-tissue and bone sarcoma workshop at the European Medicines Agency in Holland.

Welcome

Welcome to the first quarter **2024 edition of The Pledge,** the quarterly newsletter of the EHE Group. This is our **36th edition** and as usual contains a summary of the main activities of the EHE Group as we work to find better treatments and ultimately a cure for Epithelioid Haemangioendothelioma (EHE).

We hope that you will enjoy the articles in this edition, and will be inspired by all that is going on. At this point in every edition, we always sincerely thank every single person who has supported The EHE Group, whatever form that support may have taken. Their amazing energy, drive, and focus can be humbling to witness. Without them The EHE Group would not exist. We owe you all so much. ***"Just Live".***

Highlights

Patient Perspective Survey on Sirolimus is published

The EHE Group were delighted to announce the publication of the paper entitled **"The patient perspective on sirolimus for epithelioid hemangioendothelioma (EHE): results of a community survey highlighting the importance of equitable access to treatments".** Published in the prestigious journal Frontiers in Oncology, the paper presented the results of a global patient survey undertaken by the EHE Group in 2023.

EHE Group participates in important events

EHE Group members attended and participated in both the joint EMA and EORTC rare sarcoma workshop held at the European Medicines Agency in Holland in January, and the ESMO Sarcoma and Rare Diseases Congress held in Switzerland in March.

Key new Board Members announced in the US and UK

The EHE Foundation announced that Dr Guy Weinberg has joined their Board of Directors, while The EHE Rare Cancer Charity announced that Dr Paul Huang has joined their Research & Medical Advisory Board.

EHE Italia's activities, reach and profile continue to grow

The newest of the EHE Group foundations, *Associazione EHE Italia - Non Solo Laura ODV,* has continued to expand its activities and engagement in Italy, amplifying their presence and growing awareness of the disease, The EHE Group, and our global EHE patient community..

The EHE Foundation hold another great Science Saturday

Denise Robinson, Research Director of The EHE Foundation, presented an excellent high-level summary of the overall research being driven and funded by the EHE Group globally, with patient members and their supporters having the chance to ask questions.

Further details on these stories, and much more, can be found in this edition

the pledge **Edition 36**

01 Patient Support and Advocacy

Patient support within the patient community is largely provided by EHE patients to each other through multiple EHE Support Group social media pages.

At the same time, promoting greater awareness of EHE, and targeting better care and better outcomes for EHE patients globally, remains at the core of the EHE Group advocacy initiatives. The following stories cover just a few of the activities that the patient community and EHE Group are delivering.

EHE Italia presents to Oncologists

Andrei Ivanescu, President of the Associazione EHE Italia - Non Solo Laura ODV, was delighted to participate in the event 'SARCOMA OF SOFT TISSUE AND BONE - State of the art, challenges and future prospects' held on February 23rd in Padova, at the Istituto Oncologico Veneto IRCCS (IOV).

During the event, Andrei was able to present the association, its goals and purposes to a large group of oncologists, highlighting the existence of the EHE association dedicated to patients, together with the difficulties and initiatives of the last year. Andrei was particularly proud to show that EHE Italia, despite the rarity of EHE, has created a united network of patients and their supporters, and promotes important initiatives to tackle the medical challenges of this disease and support the patient group. Andrei said:

> "It was so kind of the organisers to invite me, and gave me a wonderful chance to explain who we were, and what we are trying to achieve. I was able to present key information about the Association, our goals, initiatives and the difficulties we face."

Caterina Colaci added:

> "We sincerely thank Dr. Antonella Brunello for requesting our participation to speak about the Association. We hope for more events like this, where we can present our experiences, both positive and unfortunately negative, but we are trying to have less and less of the latter.
>
> Only UNITED can we make a difference! Thank you all for your continued support! Alone we are RARE, Together we are STRONG!" ■

01 Patient Support and Advocacy

Ultra Rare Sarcomas discussed with the EMA

In early January, Hugh Leonard was pleased to be able to update the EHE patient community regarding a very positive workshop hosted by the European Medicines Agency (EMA) and the European Organisation for Research and Treatment of Cancer (EORTC), to discuss the challenges faced by ultra-rare sarcomas, defined as sarcomas with a incidence rate of less than 1 in 1,000,000 of the population. Hugh explained:

> "A large group, led by Dr Silvia Stacchiotti, and involving myself from The EHE Rare Cancer Charity and Denise Robinson from The EHE Foundation, participated in a workshop looking at how we can encourage and improve the pathway with regulators to get new treatments approved for ultra-rare sarcomas. Not only did we have the EMA participating but also the Food and Drug Administration (FDA) from the USA."

Hugh Leonard from the EHERCC and Dr Josh Sommer from the Chordoma Foundation in the US jointly presented the perspectives of patients with ultra-rare sarcomas. Senior clinicians from Europe, the UK and USA also participated, addressing a number of key areas. In addition, over 300 people participated on line, including clinicians, health care professionals, researchers, patient advocates and members of the public.

The meeting was very positive with strong alinement between the clinicians, patient groups and the regulators, all keen to continue the dialogue and to find improved ways to approve new drugs or the repurposing of existing drugs for ultra rare cancers. This is of particular importance for EHE as the EHE Group continues to seek approval of sirolimus for the treatment of EHE.

Hugh is confident that further meetings will be held and looked forward to updating the EHE community in the future.

Recordings of the presentations from the January workshop can be found at: https://www.ema.europa.eu/en/events/ema-eortc-multi-stakeholder-workshop-soft-tissue-bone-sarcoma?fbclid=IwAR31f02sR72j0i61P76HpnTrmq7bFtWEMUEztlCq0Ufa96k5nOUKZ3d-OHA_aem_AUTMaY1v3FfWRuBw1Uo2KpX-5-vYIoT6xNAHBuDfCVmZAWxleDpmsKqCM04kmTISsXuOVd6vmQTQYJ_LP8VjszWE#ema-inpage-item-64134.

EHE Advocates at the ESMO Sarcoma and Rare Cancers Congress 2024

In March Denise Robinson, Director of Research for The EHE Foundation attended the ESMO Sarcoma and Rare Cancers Congress 2024 in Lugano, Switzerland. This congress brought together world-renowned experts including researchers and clinicians, to present and discuss the latest advancements in the treatment of sarcomas and rare cancers.

Topics ranged from the role of immunotherapy for sarcomas – not specific to EHE, to our learning of the achievements of the Australian Rare Cancer (ARC) Portal, including EHE patients, and presented by Dr. Betty Zhang. Dr. Zhang impressed upon the audience the importance of such a resource for clinicians treating rare cancer patients in a vast geographic region where access to expert care is challenging.

One session featured speakers discussing new EU pharma regulations, including representatives from the European Society of Medical Oncology (ESMO) and the European Medicines Agency (EMA). Of note to the EHE community, Silvia Stacchiotti, MD, INT Milan, and Pan Pantziarka, PhD gave passionate talks highlighting patients' needs for new EU regulations that could, if implemented, improve opportunities to repurpose safe and effective drugs for use in rare diseases, including EHE.

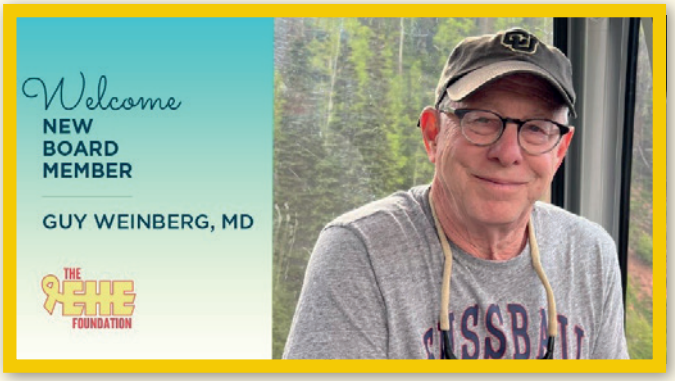
In addition to formal sessions, Denise had the opportunity to meet with other leaders of the PUSH Platform initiative, where a prospective observational study of EHE is in development. Denise shared:

> **"It is an honor to attend meetings like this, representing EHE patients around the world. It is also inspiring to witness the talent and time of world-renowned experts working alongside patients' advocates to find treatments and a cure for this disease."**

01 Patient Support and Advocacy

EHE Foundation announces new Board Member

The EHE Foundation was delighted in March to announce that Guy Weinberg, MD, had joined their Board of Directors. Internationally recognized in the field of anesthesiology, Guy is, importantly, the father of an EHE patient, bringing a multifaceted expert and personal perspective to The EHE Foundation, helping to advance the Foundation's mission to find effective treatments for EHE.



After his son was diagnosed with EHE in 2007, Dr. Weinberg formed the Center for Research and Analysis of VAscular Tumors (CRAVAT) Foundation to educate people about EHE and to support research to develop an animal model to find treatments for the disease. As a life-long scientist, Dr. Weinberg is a catalyst for EHE research, co-founding the "YAP/TAZ and TEAD: At the crossroads of cancer" workshop in 2017 at the Telluride Science Research Center in Telluride, Colorado. The workshop aims to promote collaboration across the whole Hippo-YAP/TAZ-TEAD field; however, notably for EHE, these annual meetings have increased EHE research, funding, and awareness globally.

Professionally, Dr. Weinberg is a distinguished clinician-scientist in the field of anesthesiology. The University of Illinois at Chicago Department of Anesthesiology is his professional home, where he has held various distinguished positions including Vice Head for Research, Anesthesiology. Dr. Weinberg's work on the metabolic effects of local anesthetics has been translated into an effective means of treating severe, local anesthetic systemic toxicity. He is internationally recognized for his pioneering work demonstrating the use of lipid emulsion for resuscitation from local anesthetic overdose.

Decorated with several lifetime achievement awards, including the European Society for Regional Anesthesia Karl Koller Lifetime Achievement Award in 2019 and the American Society for Regional Anesthesia and Pain Medicine's Gaston Labat Lifetime Achievement Award in 2020, Dr. Weinberg continues to give invited academic lectures on translational medicine in anesthesiology.

The Pledge wants to add its voice to those of the global EHE community in congratulating Dr. Weinberg on his new appointment and to thank him, not only for all he has contributed to date to EHE research, but also for all that he will add in the future. We are truly grateful. ■

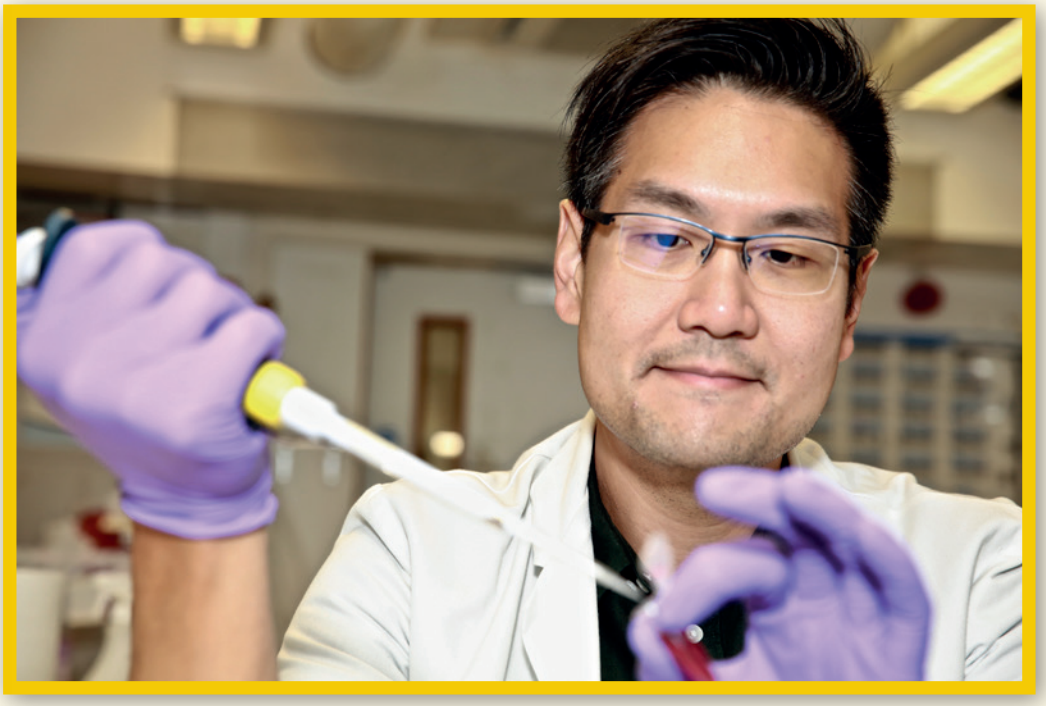
New member joins EHERCC Advisory Board

In mid-January, The EHE Rare Cancer Charity (UK) was excited to be able to confirm that Dr Paul Huang had joined the charity's Research and Medical Advisory Board. Dr Paul Huang is Head of the Molecular and Systems Oncology Laboratory at the Institute of Cancer Research in London, UK. He received his PhD in Biological Engineering from Massachusetts Institute of Technology in 2008. His laboratory focuses on understanding aberrant signalling networks and drug resistance in sarcomas, with the goal of developing biomarkers and new therapies for these diseases. Dr Huang is the Deputy Director of the Joint Royal Marsden-ICR Sarcoma Research Centre, one of the largest sarcoma research centres in Europe. He serves as Vice Chair of the Pathology & Translational Research Committee of the EORTC Soft Tissue and Bone Sarcoma Group and on the Board of Directors of the Connective Tissue Oncology Society. He was elected a Fellow of the Royal Society of Biology in 2020.

Hugh leonard was thrilled to be able to welcome Dr Huang:

> **"We are really delighted to be able to confirm that Dr Paul Huang has joined the EHERCC Research and Medical Advisory Board, and welcome him to the team. Dr Huang works at the Institute of Cancer Research, which is a sister organisation of the Royal Marsden Hospital, where he continues to be a great champion of the EHE cause. He is a key collaborator with Dr Stacchiotti and her team in Milan on the research that the EHE Group continues to fund, including research to identify possible EHE biomarkers. It is hard for us to overstate how delighted and lucky we are to have Dr Huang join our Advisory Board."**

Our regular readers will have seen Dr Huang appear on multiple occasions in past editions of The Pledge, and The Pledge is also delighted to welcome Dr Huang to the UK Advisory Board. ■



01 Patient Support and Advocacy

EHE Italia continues to grow

Associazione EHE Italia - Non Solo Laura ODV, based in Milan, is the newest of the EHE Group foundations. 2024 saw EHE Italia start the new year with renewed ambition and a call to arms for their supporters everywhere.

> "Join the beating heart of solidarity: donate to EHE Italia - Non Solo Laura, because together we can make a difference in the fight against Epithelioid Hemangioendothelioma. Every contribution counts, every act of love makes the future brighter. Donate today for a better tomorrow!"

Shortly afterwards EHE Italia - Non Solo Laura launched their 2024 membership campaign. Andrei Ivanescu, President of the Association said:

> "Over the past year, we have been able to carry out many initiatives, such as the consent document, a first mapping of reference centres, several meetings with doctors and researchers, as well as a fundraising event like the Artisan in Fiera. All of this was possible thanks to the will and efforts of people, from patients to family and friends, who have somehow come in contact with this cancer, and have seen in the association a hope and a possibility to make a difference."

Caterina Colaci, EHE Patient and head of communications added:

> "What we need now is to be able to expand this group, get more people to bring their ideas, and contribute to this project. Whether it's making available our own skills, or even just our own time, only together can we continue to make progress and develop new initiatives. Join us on this journey, help us continue the fight against this cancer, for yourself or a loved one, each and every one of us can make a difference. Alone we are RARE, together we are STRONG!"

At the same time, Andrei was pleased to be able to announce another excellent initiative to spread awareness of the Association and of EHE:

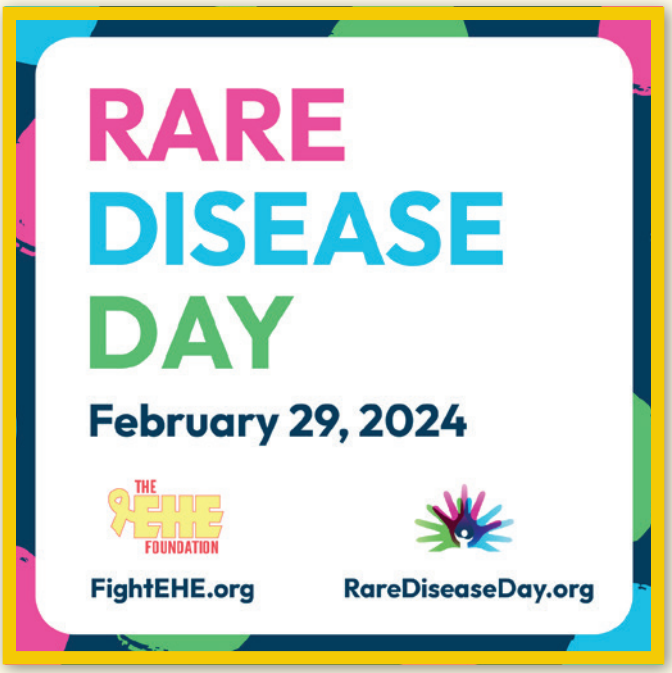
> "We are happy to inform you that an interview done for FamilyLife, a blog by TGCOM24, has been published with the aim of giving more visibility to our disease and our association. We thank Alexandro Fiumara and the editorial staff of FamilyLife for giving us this opportunity."

For those who are interested, you can read the article at: https://familylife.tgcom24.it/2024/01/15/ehe-italia-insieme-per-sconfiggere-un-male-silenzioso/

We love the ambition, the drive and the team work of EHE Italia. **"Ben fatto. Continuate così".**

01 Patient Support and Advocacy

Rare Disease Day 2024



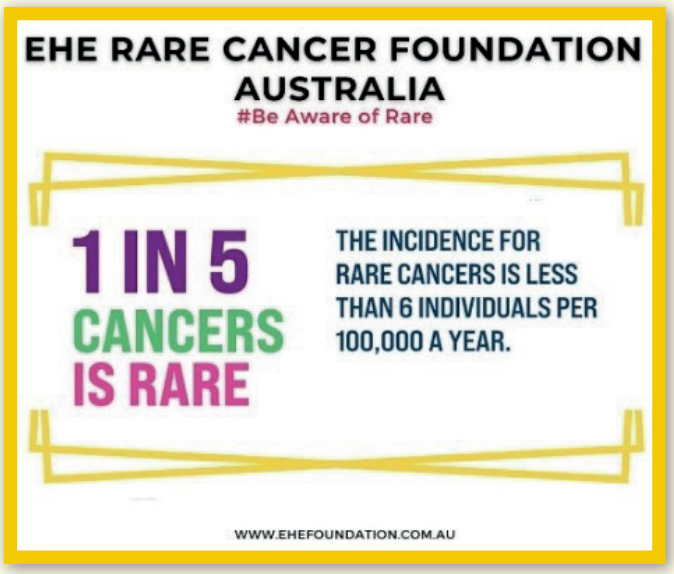
Rare Disease Day was February 29th, a very special rare day that The EHE Foundation were keen to celebrate, as Maggie Cameron, Director of Development & Communications explained:

> "We asked our community to help us build EHE awareness by submitting their EHE stories so that we could share them on our social media platforms and website to shine a light on EHE and rare diseases! Throughout the month, we shared the stories of three EHE patients, each navigating this disease in their own way. Their stories are included on our Faces of EHE page on The EHE Foundation website at **www.fightehe.org** . We also launched our national awareness and fundraising event, the 2024 EHE Fun Run & Walk. By registering and receiving an EHE ***"Just live."*** T-shirt, participants are spreading awareness each time they wear that shirt. Our community hosts events all over the country allowing EHE awareness to spread far and wide."

Rare Disease Day is the globally coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Collectively, they aim to change and improve the lives of the 300 million rare disease patients worldwide.

The EHE Rare Cancer Foundation Australia also wanted to recognise Rare Diseases Day! Jonthan Granek, Director of the Foundation said:

> "A rare disease means that less than 5 in 10,000 people have it. EHE is not just a rare disease: EHE is an ultra-rare disease because EHE diagnoses are less than 1 in 1,000,000! There are many challenges faced by rare disease communities, which is why days such as today are important for raising awareness about EHE and advocating for improved outcomes for our patient community."



The Rare Diseases Day message was also taken up by Associazione EHE Italia - Non Solo Laura ODV in Italy. Caterina Colaci explained:

"This day unites us in supporting those who fight every day against rare, often little known and understood diseases. World Rare Diseases Day is celebrated annually on February 28 (or 29 in leap years) to raise awareness among the public and institutions about the challenges faced by patients with rare diseases and their families. For this reason, World Rare Disease Day wants to give voice to these patients and their associations, and all they fight for, under the banner:

Rare is many. Rare is strong. Rare is proud.

Let's join hands and hearts to spread awareness, empathy and solidarity. Every story is unique, but together we can make a difference. Let's share knowledge, embrace diversity and work together towards a future where no one has to face the struggle alone. We as Associazione EHE Italia - Non Solo Laura ODV, fight every day to raise awareness and shine a light on this ultra-rare tumor called Epithelioid Hemangioendothelioma."

01 Patient Support and Advocacy

Another great Science Saturday

The EHE Foundation was delighted to invite EHE patients from around the globe to participate in their latest Community Connections videoconference on 24th February. Entitled **"Patient-Powered Research"**, Denise Robinson, Director of Research for the Foundation, presented a detailed overview of the main research projects that the EHE Group are engaged with and which depend on patient participation. Densie explained:

> **"In an ultra-rare cancer like EHE, patient participation is critical to helping researchers advance their knowledge of this disease."**

Denise recognised that patient participation comes in many forms including providing their clinical data; donating bio-samples; participating in studies and trials; and driving fundraising to help fund critical research. Denise concluded with huge thanks for all that patients do to support the EHE Group, noting that:

> **"Together, PATIENTS can impact and improve outcomes for all EHE patients!."**

The presentation, and the question and answer session at the end were enthusiastically welcomed with everybody agreeing that this had been a wonderful, informative and empowering session. The EHE Foundation was also delighted to announce that the whole event had been recorded and can now be watched at

https://fightehe.org/community-connection/science-saturday-patient-powered-research/

We congratulate The EHE Foundation, and particularly Denise Robinson, for hosting and presenting such a great event. We also encourage patients and their supporters to watch the recording and see the excellent information that is shared. ■

Promoting the EHE Survivors Page

Fiona Ross posted a reminder to the EHE patient community about another EHE Facebook page that was established in support of EHE patients and is available only to patients. Fiona said:

> **"Just for your information, EHE patients can apply to be part of the EHE Survivors page. It is a safe space where patients only can ask questions and offer support to each other so you don't need to post anything anonymously. The administrator is JoAnna Jones."**

The page was established to provide a safe and confidential place where patients could post questions, voice concerns, high-light their worries and frustrations, and generally raise any issues, secure in the knowledge that their content will only be seen by fellow patients.

This is an important component of the overall EHE patient support structure and we want to thank Fiona for raising awareness of this important page for both new and more-established members of the group.

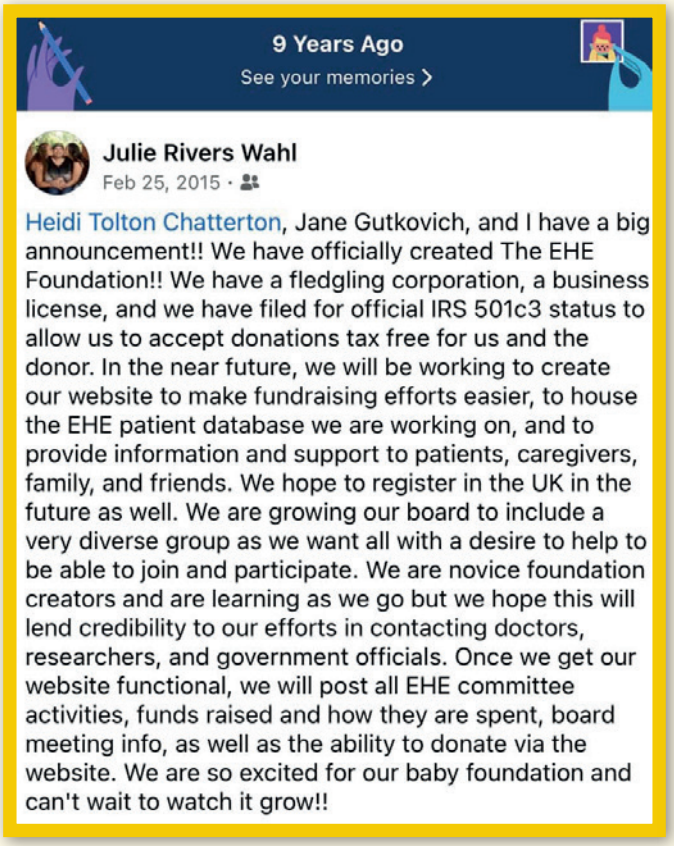
01 Patient Support and Advocacy

Happy birthday to The EHE Foundation

Julie Wahl posted news in February of the 9th birthday of The EHE Foundation by sharing a repost of the original announcement in 2015 that The Foundation has gone live.

Julie Wahl commented:

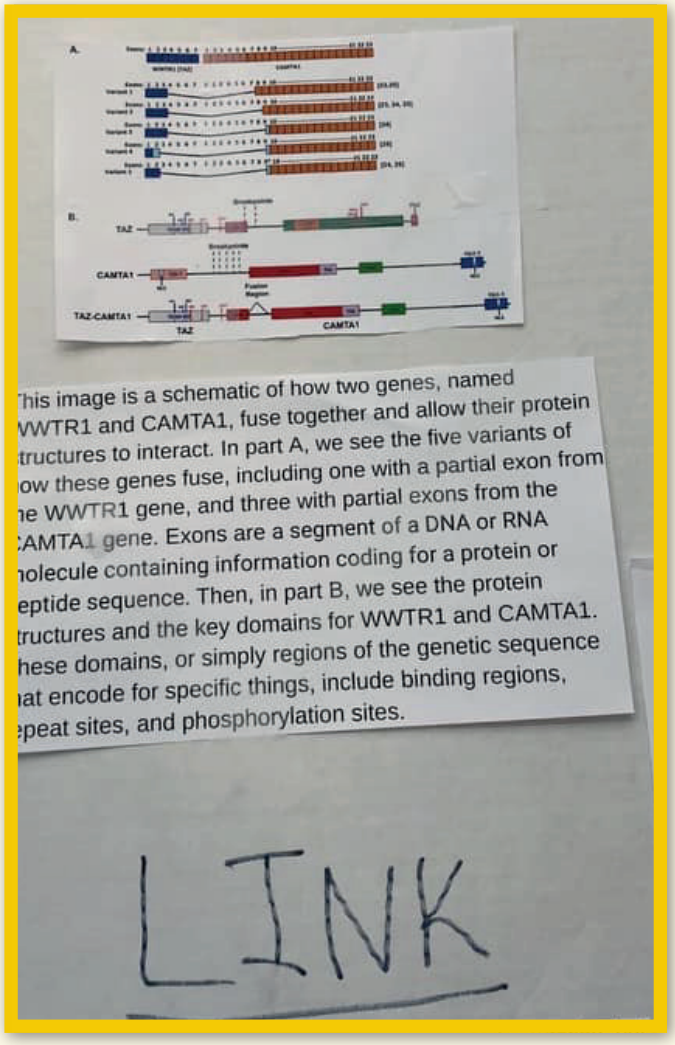
> "It is amazing to think that nine years have already passed since our Foundation went live. It is even more amazing to think how much we have achieved in that time. In 2015 we had no website; no money(!!); had not been able to isolate the fusion protein; we had no models of the disease; we were only aware of one dedicated research team working on EHE, in Brian Rubin's lab; biomarkers were a dream; repurposing drugs a fantasy; tead inhibitors had not even been thought of; large scale observational studies just a wish; thoughts of a patient registry were embryonic; and we had no idea if the Foundation would work! But we did have drive, focus, dedication, and a passionate belief that together we could beat this wretched disease, and look what we have all achieved together! It really is nothing short of miraculous. As we keep saying, **"Alone we are rare, together we are strong!"** But there is so much more to do, so please don't relax. Please join the patient registry; please support the EHE biobank; please keep the fundraising going. Let's see what we can do in the next nine years!"

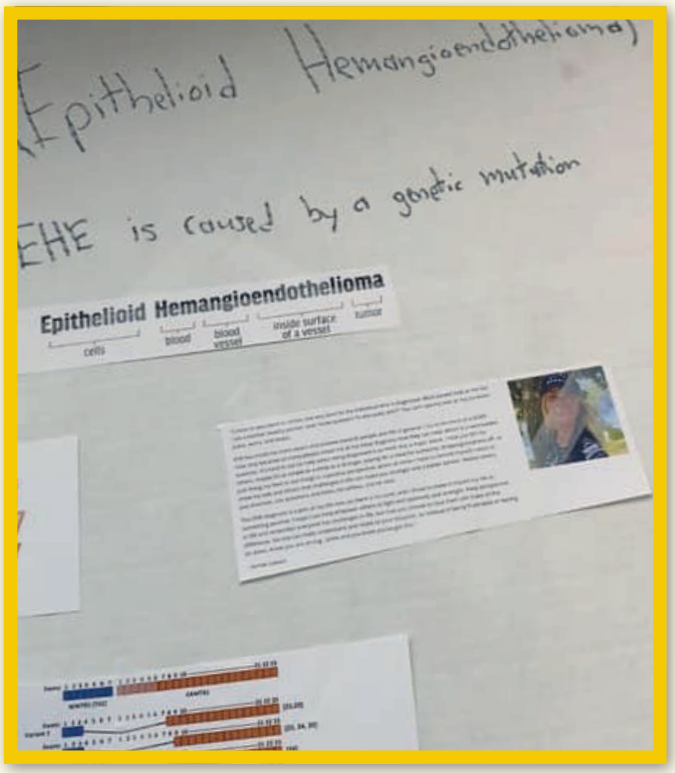


Wonderful words Julie. We want to congratulate everybody at The EHE Foundation for all their brilliant work and achievements.

A proud Mama

Aimee Liebert was very proud indeed to post news of her son's engagement with EHE. As a freshman in high school, he chose EHE as the subject of his semester final in Honors Biology, and spent time and care in developing his presentation. Here are some of the excellent presentation materials he developed.





Her son also wanted to know who was looking after his mother's oncological care and asked if he could accompany Aimee to her next consultation. Aimee explained:

> "It was a proud mama moment when my son asked to come to New York with me and meet my doctor at MSK in person, as he wanted to make sure his Mom has the best doctor taking care of her. He came to my appointment in December and met Dr. Tap and left saying how smart and nice he was, and he felt better knowing he was taking care of me."

We love to see such a caring attitude from Aimee's son and completely understand why she is so proud of him. ■

01 Patient Support and Advocacy

EHE Global Patient Registry is growing

The EHE Foundation were delighted to be able to report in February excellent early progress with regard to the EHE Global Patient Registry.

> "Over 200 people from around the world have joined the EHE Global Patient Registry representing 19 countries. This is a great start, but we want many more. It is hard to overstate the importance and benefit of every single patient contribution."

Denise Robinson continued:

> "The value and benefit of a registry is directly related to the number of patients that are included. So please, if you haven't already joined, we encourage **YOU** to please consider joining today! Go to **https://eheregistry.iamrare.org/** to find out more and register to join. Your input will help doctors, researchers, and other patients know, for example, how many people have EHE that is like your disease. By collating and analysing this data your input may lead to break-through understanding of EHE. Please don't just leave it to others. Join the registry today."

If anybody has any questions or concerns about the registry, then please reach out to your nearest EHE Group foundation who will be able to help. ■

Breaking down language barriers

One of the challenges faced by many EHE patients is accessing information about EHE in their own language when that is not English. EHE Italia recognised this problem immediately and have set themselves a goal of ensuring that they can provide translations of important and informative documents to the Italian EHE community. This started with the ESMO Consensus papers, both the official and patient-friendly versions, and now include the Pledge. Andrei Ivanescu commented:

> "We were delighted that we were able at the start of this year to share an Italian version of Edition 35 (Q4 2023) of The Pledge, the quarterly newsletter of the EHE Group. There is so much in this newsletter about what the global EHE community is doing. It's very uplifting and we were determined therefore that this document should be available to our EHE patients and supporters in Italian."

Congratulations to Andrei and the whole EHE Italia team for this wonderful initiative.

01 Patient Support and Advocacy

EHE 360 Global Patient Conference 2024

The EHE Foundation continued throughout the first quarter to invite patients and all other EHE community members to join the 2024 EHE 360 Global Patient Conference. This will be a virtual event featuring an international group of clinicians, researchers, and EHE advocacy groups bringing the latest information about EHE to patients and caregivers. Back by popular demand, the "Ask the Expert" session allows participants to ask the expert panel questions about EHE and hear their insights LIVE!

Participants in the previous EHE 360 events in 2022 and 2023 found the conferences to be empowering, providing them with a broader understanding of EHE, the research that is ongoing, and a deeper connection to the EHE community.

Jenny Case Kovach, President of The EHE Foundation was particularly keen to encourage the patient community to take part:

> **"Don't miss this opportunity to come together with other EHE patients, families, caregivers, doctors, researchers, and advocates to learn, collaborate, and advance the fight for effective treatments and a cure for epithelioid hemangioendothelioma (EHE)."**

There is no cost to attend, but as in previous years, registration is required and can be easily completed using the link on The EHE Foundation website.

Denise Robinson was also keen for everybody to participate, and wanted to thank the excellent line up of presenters and expert panellists that would be taking part on the day:

> **"We could not be more grateful to the superb group of presenters and panellists who will ultimately be responsible for making this such a positive, educational process for all who participate. We thank all of you for supporting our patient community by giving your time and sharing your knowledge."** ■

2024 EHE 360 Global Patient Conference Presenters

Brian Rubin, MD, PhD
CLEVELAND CLINIC
EHE 101: What You Need to Know

Nadia Zaffaroni, PhD
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI DI MILANO
Identification of Biomarkers for EHE to Inform Patient Management and Potential Therapeutic Targets

Tom Wei-Wu Chen, MD, PhD
NATIONAL TAIWAN UNIVERSITY HOSPITAL
Myth Buster: A medical oncologist's view on the management of EHE

Michele Molinari, MD, MSc, FACS
UNIVERSITY OF PITTSBURGH MEDICAL CENTER
Treatment of Hepatic EHE

Hugh Leonard, Chair of Trustees
EHE RARE CANCER CHARITY (UK)
EHE European Research Collaboration

Ajaybabu Pobbati, PhD
CLEVELAND CLINIC
Targeting EHE: Pocket Science and Other Approaches

Fiona Ross, Board of Directors
SARCOMA CANCER FOUNDATION OF CANADA
ProCARE Canada Research Update

Pan Pantziarka, PhD
ANTICANCER FUND
Drug Repurposing: Emerging Opportunities to Identify Treatments for EHE

Greg Cote, MD, PhD
MASSACHUSETTS GENERAL HOSPITAL CANCER CENTER
Clinical Trials for EHE

Andrei Ivanescu, President
EHE ITALIA ASSOCIAZIONE NON SOLO LAURA ODV
EHE Italia

Melissa Burgess, MD
UPMC HILLMAN CANCER CENTER
EHE Expert Panelist

Rashmi Chugh, MD
UNIVERSITY OF MICHIGAN ROGEL CANCER CENTER
EHE Expert Panelist

Elizabeth Davis, MD
VANDERBILT UNIVERSITY MEDICAL CENTER
EHE Expert Panelist

William Tap, MD
MEMORIAL SLOAN KETTERING CANCER CENTER
EHE Expert Panelist

02 EHE Research

Here you will find updates on just some of the EHE research that is ongoing.

This is being supported by the EHE Group and EHE patient community, either through direct funding, but also by providing multiple forms of patient data and experience. It is only by undertaking this research that the EHE Group will ultimately be able to help find new ways to treat and manage EHE.

We hope you will be inspired by the work taking place and the dedication and skill of the researchers that are delivering it.

Sirolimus patient perspectives survey results published


The patient perspective on sirolimus for epithelioid hemangioendothelioma (EHE): results of a community survey highlighting the importance of equitable access to treatments

Denise Robinson[1] Hugh Leonard[2] Giacomo Giulio Baldi[3]
William D. Tap[4] Robin L. Jones[5] Silvia Stacchiotti[6] Pan Pantziarka[7,8*]

The EHE Group were delighted to report that a paper addressing the important issue of patient access to the drug sirolimus (one of a class of drugs known as mTOR inhibitors) had been published in Frontiers in Oncology, a prestigious, peer-reviewed scientific journal, on 26th February. This paper, entitled **"The patient perspective on sirolimus for epithelioid hemangioendothelioma (EHE): results of a community survey highlighting the importance of equitable access to treatments"** presented the results of a survey of the global EHE patient community, conducted in 2023, about their access to, and results of treatment with, sirolimus.

The survey, coordinated by Denise Robinson, Director of Research of The EHE Foundation, and Hugh Leonard, Chair of Trustees of The EHE Rare Cancer Charity UK, was undertaken to support the ongoing application to the European Medicines Agency (EMA) for a label extension of sirolimus (also called rapamycin and marketed by Pfizer under the tradename Rapamune®) to include the treatment of EHE. While sirolimus has been globally approved and widely used for many years, mainly as an immunosuppressant, it can still only be prescribed to EHE patients 'off label' as it has not been formally approved for the treatment of EHE. This means sirolimus is only available to patients who can access the drug off-label, resulting in inequality of access to this important treatment.

Denise Robinson was instrumental in developing the survey, and explained the background to why a label-extension is so badly needed:

> "There is a growing body of evidence, including the experience of our patient community, that sirolimus is now the leading front-line drug for the systemic treatment of EHE. In 2021 the ESMO paper **"Epithelioid hemangioendothelioma, an ultra-rare cancer: a consensus paper from the community of experts"** recognised, when comparing different drugs used to treat EHE, that **"the highest clinical activity has been reported for mTOR inhibitors"** and confirmed that **"the panel [of experts] agrees that these [mTOR inhibitors] represent the preferred treatment options for patients with advanced and moderately progressive disease."**

However, because sirolimus is not formally approved for EHE and can only be prescribed off-label, many patients cannot access it if their doctor, or hospital, or national health system won't allow off-label use. Even if they can access off-label prescription, the drug may need to be self-funded if it is not funded by their health system, resulting in sirolimus being out of reach for most patients. This creates a huge inequality in the access to the drug and is why we are determined to secure regulatory approval for a label extension.

The results of the sirolimus survey, that 130 of the EHE patient community participated in, are an excellent example of why patient data is so important. The data supports the position expressed in the ESMO paper described above, namely that mTOR inhibitors like sirolimus are being successfully used in the treatment of EHE. It also shows that these drugs are not equally accessible for all patients due to only being available off-label.

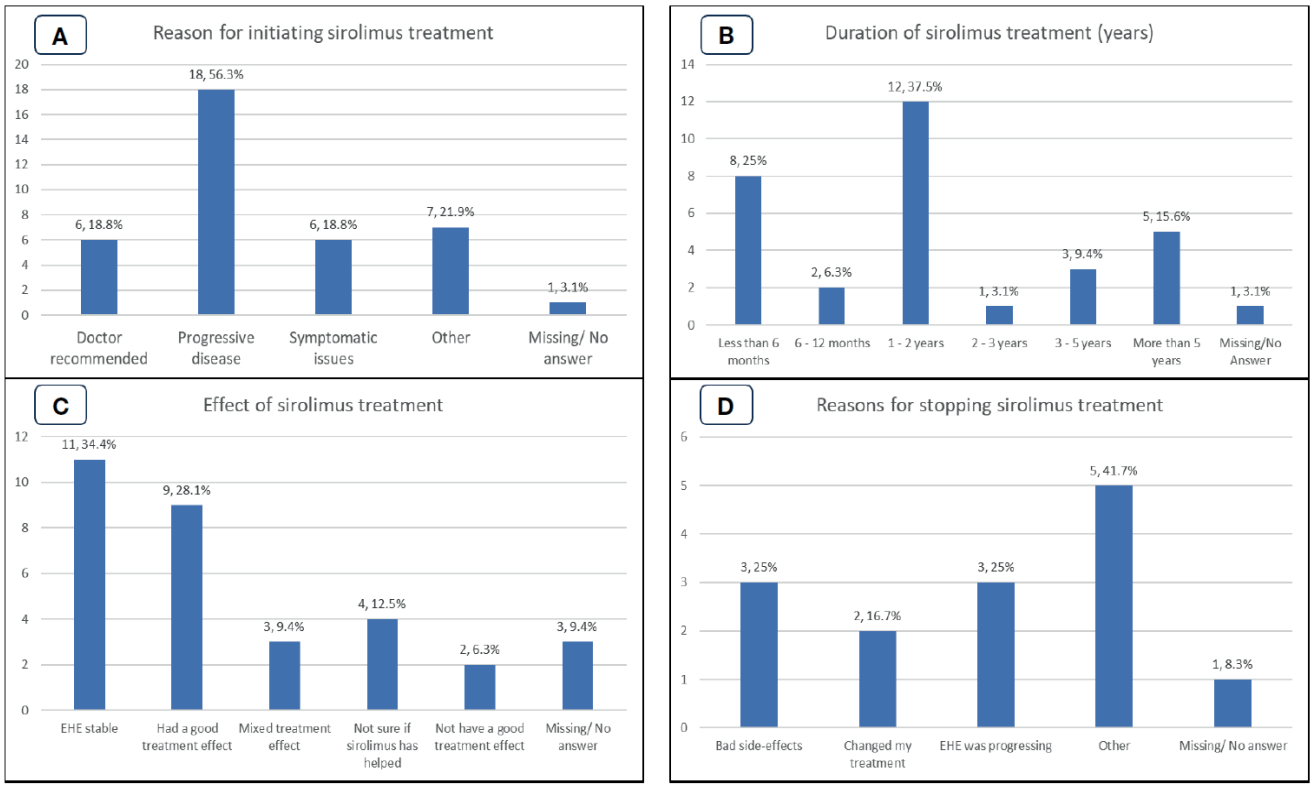


FIGURE 3
Patient experiences of the Group S (sirolimus) cohort. **(A)**: Reasons for initiating sirolimus treatment. **(B)**: Duration, in years, of sirolimus treatment. **(C)**: Patient perspective on the effect of sirolimus treatment. **(D)**: Reasons for cessation of sirolimus treatment.

Hugh Leonard expanded on why the published paper is important to the regulatory process, not only with the EMA in Europe, but also with other regulators like the FDA in the USA:

> "Regulators want to hear and understand the experience and perspective of the patient community. However, in presenting such information, we need to be able to show that the data was collated and analysed in a rigorous manner, in line with accepted scientific practise, and that the results and conclusions drawn are supported by the underlying data. The publication of the results in a peer-reviewed paper confirms all these requirements have been met and allows the survey to be accepted and considered by regulatory bodies in their deliberations."

Jenni Kovach, President of The EHE Foundation, was also excited by the publication:

> "This right here is what our community can do by working together. First two authors listed... The EHE Foundation US and EHE Rare Cancer Charity UK with participation from many of you. AMAZING!."

Both Hugh and Denise want to thank the other authors of the paper, Giacomo Giulio Baldi, MD, Pan Pantziarka, PhD, Silvia Stacchiotti, MD, Professor Robin Jones and William Tap, MD for their excellent hard work, guidance, and commitment in helping to produce the paper. Huge gratitude is also extended to The EHE Rare Cancer Foundation Australia, EHE Canada, and EHE Italia Associazione Non Solo Laura ODV, all of whom were instrumental in mobilising support and participation of EHE patients. But the biggest thanks, without doubt, goes to each and every one of the 130 EHE patients who took part in the survey. Without their fantastic support, there would have been no data to work with.

If you wish to read the paper, it can be found at:

https://www.frontiersin.org/journals/oncology/articles/10.3389/fonc.2024.1367237/full ■

Drug Repurposing for EHE

'Drug repurposing' is the process whereby researchers and clinicians look at drugs that are already proven to be safe and are approved for human use for other diseases to see if a drug shows sufficient activity against a new disease (that it is not approved for) such as EHE. This is a growing area of drug development research and is a hugely important part of any cancer research programme. Using drug repurposing it is possible to identify drugs that can provide effective treatments in a far shorter time frame than developing new or novel compounds. Denise Robinson explained:

> "Identifying, developing, testing, and successfully getting approval for a truly novel drug is a long and complex process that can easily take ten or more years and hundreds of millions of dollars. In the case of an ultra-rare sarcoma, like EHE, that process may be even longer. If we can identify an existing drug and generate data that shows activity against the disease, then we can use that data to seek an extension of the drug's label which could be much quicker because the drug has already been approved for human use. It may still take several years to prove that activity and get the regulatory approval needed but in short, we can deliver new treatments faster!"

Repurposing is therefore a core part of the EHE Group's ongoing research programme and future EHE strategy. In the following sections we have described the different ways that the EHE Group is working to deliver the repurposing of drugs for EHE patients.

Repurposing Sirolimus for EHE

The EHE Group is currently working hard to secure an approval from the European Medicines Agency (EMA) for a label extension of sirolimus for the treatment of EHE. Expert clinicians and advocates believe the application to the EMA is justified given a growing body of evidence demonstrating that sirolimus is safe

and effective for the treatment of EHE. The evidence in consideration is based on small data sets and evidence reported from clinical practice over the last ten years, initially based on the work promoted by Dr Silvia Stacchiotti and her team at INT in Milan, Italy.

The process of seeking such an approval from the EMA is being undertaken by a group comprising the EHE Rare Cancer Charity UK, The EHE Foundation, sarcoma clinical experts both in Europe and the US, and The AntiCancer Fund (ACF), a specialist not-for-profit organisation focused on drug repurposing. Hugh Leonard and Denise Robinson are both working members of this EHE repurposing group, representing the EHE global patient community. Hugh Leonard outlined the history and current status of this application:

> "The ACF submitted 'sirolimus-for-the-treatment-of-EHE' to the new EMA repurposing pilot process in 2022. The EMA accepted the proposal and the ACF then reached out to Dr Silvia Stacchiotti and the EHE Rare Cancer Charity to bring clinical expertise and patient advocacy into the EHE repurposing group. We were of course very pleased and hugely grateful to the ACF for including us. The pilot process was established by the EMA to try and facilitate and accelerate repurposing of drugs for ultra-rare cancers. We have so far passed through two rounds of the EMA's Scientific Advice programme. This has allowed us to gain a better understanding of what the EMA require in terms of the data they ultimately want to see. Overall, the EMA have been helpful and constructive, but the process takes a long time."

Dr Lamar (far left) and his team

The EMA recognise that their process is slow and in January the EHE repurposing group participated in an EMA public workshop in Amsterdam, reported separately in this section of The Pledge, to discuss ways that the process could be improved. Recordings of this workshop can be found at:

https://www.ema.europa.eu/en/events/ema-eortc-multi-stakeholder-workshop-soft-tissue-bone-sarcoma#ema-inpage-item-64134

At the end of March an additional informal meeting was held with the EMA to review two new study proposals submitted by the EHE repurposing group, and to answer questions the group have with regard to the Scientific Advice being sought. Hugh Leonard said:

> "While we would love the process to be faster, we are pleased that the dialogue is continuing and we hope that we can report further progress in the near future."

Drug Repurposing Research in Progress

While sirolimus has demonstrated having activity for EHE, it is only one drug and will not work in all cases. The EHE Foundation (US) are funding two significant research projects that each aim to screen other existing FDA-approved drugs to identify those that may have activity for EHE.

Dr Lamar (far left) and his team

The first is led by Dr John Lamar, based at the Albany Medical College in New York. Dr Lamar's group are investigating the use of pre-clinical EHE models to identify druggable pathways to treat EHE to reveal pathways that can be targeted with existing FDA-approved drugs to either eliminate EHE or prevent its growth.

The second is led by Dr Ajaybabu Pobbati, based at the Lerner Research Institute at the Cleveland Clinic. Dr Pobbati's research was initiated in 2022, and extended in 2023, and aims to repurpose an FDA-approved drug for EHE. Work continues to further investigate drugs to regulate the TAZ-CAMTA1 fusion protein.

Dr Ajaybabu Pobbati

Both projects have already identified some interesting candidates and work is progressing to test these drugs in mice and human cell lines to further understand and verify the therapeutic mechanisms involved.

We want to thank both Dr Lamar and Dr Pobbati, and their respective teams for the excellent work completed so far. We hope we can share more positive news from both labs in the future.

EHE Models Are Critical for Drug Repurposing

At first glance it may seem strange that we have included EHE models in this drug repurposing section. However, it is ethically not possible to test drugs in humans without generating evidence of the proposed drug's efficacy and safety in pre-clinical models. Data generated from research in pre-clinical models is then used to support the applications to conduct clinical trials including human subjects. So without models of the disease, drug repurposing programmes cannot efficiently make progress.

EHE biobanks serve as essential resources in drug development and repurposing. EHE patients donate tissue and fluid taken during a surgery, transplant, or fluid draining procedure, which in turn enables scientists to use these EHE cells (from the donated tissue) to make EHE disease models. The EHE Biobank (US) has partnered with researchers to generate EHE human cell lines which The Foundation hopes will be available for drug developers later this year. Additionally, tissue samples donated through research at the INT in Milan have led to the first successful patient-derived xenograft (PDX) model of EHE. A PDX model is made when tumor tissue from a patient is implanted in mice, which then allows the tumour to grow, sections of which are then transplanted in more mice, hopefully allowing more and more tumour tissue to become available . Importantly, INT has also developed an EHE cell line from their PDX model. Additional models are in progress.

We therefore want to thank everybody who has and continues to support the EHE biobank initiatives and ask all EHE patients to support the biobanks going forward. It is your tissue that may one day lead to a therapeutic breakthrough for EHE. It is both that simple and that important.

If you are considering surgery, a transplant, or might have fluid drained from your abdomen or lungs please contact the EHE biobank in your region. Details can be found on the different EHE Group websites. ■

02 EHE Research

UK EHE Biobank Access Committee being finalised

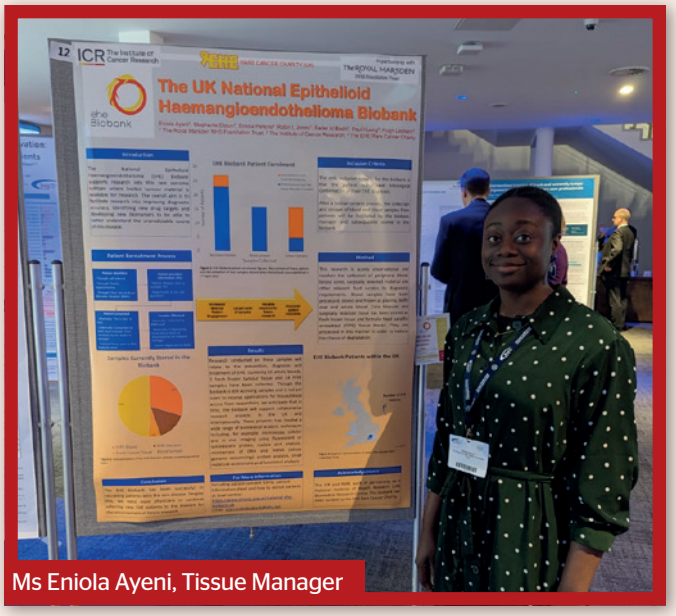
The simple objective of the UK National EHE Biobank is to continue to collect all biospecimens that may become available from the treatment and care programmes of EHE patients in the UK, and to make sure that these are captured for future research. Biospecimens will include tissue from biopsies, resections and transplants; longitudinal blood samples; plural effusion samples; and possible autopsy samples.

Progress has been very good. At the time of writing a total of 39 patients have enrolled in the biobank with the following samples now captured:

27 x patient blood samples

24 x biopsy samples; and

3 x live tissue samples



Ms Eniola Ayeni, Tissue Manager

This is excellent progress, but as Hugh Leonard explained, capturing and storing the samples is of little value if they are not used for research. Hugh went on:

> "Access for researchers is now critical, as we have potentially meaningful biobank samples captured. Access however has to be very tightly controlled, both under the ethics approval granted for the biobank before it even started, and under the relevant UK legislation relating to human tissue use. We will therefore be meeting in April with Professor Robin Jones, Principle Investigator for the biobank, Dr Paul Huang and the Biobank Tissue Manager to agree the structure, composition and members of the Access Committee."


Dr Paul Huang


Prof Robin Jones

Watch out for further details in the next edition of **The Pledge**.

PUSH Platform offers hope for ultra-rare sarcomas

EHE is one of nearly 80 diseases collectively known as ultra-rare sarcomas which each have an incidence ≤1 case/million people per year. Ultra-rare sarcomas include bone and soft tissue tumours, that collectively constitute around 20% of all sarcoma cases. This means many ultra-rare sarcoma patients face challenges that all patients with ultra-rare cancers face, such as:

- Having minimal data on the natural history of their disease;
- An acute lack of research funding to comprehensively study ultra-rare diseases;
- Few and poorly defined treatment options; in EHE there are no disease-specific approved treatments
- Major hurdles in designing and performing large, randomised clinical trials within a reasonable timeframe and cost due to the extreme rarity of patient populations
- Difficulties in drug development and access due to low interest from commercial drug developers

To try and address these serious challenges, a broad group of representatives from the global sarcoma community under the umbrella of the **Connective Tissue Oncology Society** (**CTOS**), including clinicians, scientists, patient advocates and non-profit organisations are establishing a consortium to address these hurdles, through the development of a new project called the **PUSH** (**P**ushing **R**are **S**arcoma beyond **H**ope) Platform. The central aim of the PUSH Platform is to maximise the knowledge that is gained from interacting with and treating every single patient affected by an ultra-rare sarcoma and to support developing new treatments to improve outcomes and quality of life.

EHE is one of these ultra-rare sarcomas, and so the EHE Group immediately supported the development programme. Hugh Leonard and Denise Robinson are members of the PUSH Executive Committee, as well as sitting on various working groups that have been created to help take the project forward.

Ultimately it is hoped that a substantial number of institutes and academic centres across the globe will join the project, forming the PUSH Consortium, giving the PUSH Platform real momentum and an ability to change the landscape for ultra-rare sarcomas. This will include collating relevant prospective and retrospective data from substantial numbers of patients from around the world. PUSH will incorporate data from a huge range of different sources that will in turn be used, with regulatory involvement and input, to define and undertake appropriate new prospective studies and associated analyses to help deliver new treatments for patients in faster, lower-risk, well understood and defined processes. PUSH is designed to also include prospective clinical trials. The first study will aim to support the prospective assessment of sirolimus as a treatment for progressive EHE.

Hugh and Denise agreed:

> "All participants understand that PUSH will initially be a huge undertaking, but with the people already involved and the obvious commitment to getting this platform up and running, we have no doubt that it will be successful. This is so important as ultra-rare diseases can only be addressed by engaging with the global patient community. Coordinating this from scratch for each rare disease study that is necessary means time scales will remain very long and costs and execution risk will continue to be very high. This in turn results in limited appetite to be involved and significant difficulty in funding the work. The PUSH Platform, with its established international consortium, agreed legal structures and coherent operations plans and procedures will address these challenges by significantly reducing times, cost and risk, and so encourage participation and funding."

The Platform is still being developed but the concepts were presented at the 12 January EMA Workshop "**EMA and EORTC multi-stakeholder workshop on soft tissue and bone sarcoma**". The workshop is reported separately in this section of The Pledge, but as the PUSH Platform will help to address many of the challenges faced by ultra-rare cancers, it was not a surprise to see the PUSH concept well received by one of the world's largest regulators.

We look forward to further updates in the future. For those who want more details about the platform, please go to the PUSH website at: http://www.push-platform.org/ ■

Genomic testing is under review in Australia

In mid-February, Jonathan Granek, Director of The EHE Rare Cancer Foundation in Australia posted news of an important new study being undertaken in Victoria, Australia. Jonathan explained:

> "We are seeking patients treated in Victoria, Australia to participate in a research study about experiences of accessing genomic tumour testing in Victoria. This is a consumer-led study developed by the VCCC Alliance Precision Oncology Consumer Reference Group, of which I am a member. This project aims to support the development of an equitable roadmap to genomic testing in Victoria, and has the following objectives:
>
> 1. Generate knowledge that will help government and other decision makers consider the needs and experiences of patients when making decisions about funding access to testing.
> 2. Generate knowledge that will provide insight into equity issues in regards to access to genomic testing via clinical trials and standard care.
> 3. Provide insights into patient experiences of standard care and suggestions for improvement to assist health professionals to develop patient-centred approaches to precision medicine.
> 4. Provide a snapshot of patient experiences that can be used as a yardstick for measuring progress in the future.
>
> To achieve this, the researchers are exploring genomic testing in Victoria from a patient perspective, with a focus on access of uptake and consumer experiences. Capturing EHE experiences here is valuable and important!"

Genomic tests look at a patient's tumour sample that is usually taken via a biopsy. The tests analyse the DNA contained in the tumour for any irregular patterns that may indicate a prognosis or point to a particular cancer treatment that would be the most appropriate course of action. These tests are different from the type of genetic testing that looks at an individual's inherited cancer risk (passed down through families) from normal tissue or blood. Genomic testing is an example of personalised cancer care, which tailors treatments to patients' exact tumour make-up.

Jonthan also wanted to stress that past experience of genomic testing was not required:

> "If you haven't heard of genomic testing, you can still take part because it is really important for the researchers to understand why people may not have accessed testing.
>
> The survey takes about 15-30 minutes to complete (depending on if you have had testing or not) and can be accessed here **https://redcap.link/f6mvsy27**." Please join this important study if you can. Your views and experience are important." ■

HE Italia provides support for the Italian Sarcoma Group

Associazione EHE Italia - Non Solo Laura ODV were excited to inform their Italian supporters, and the EHE global community about an important commitment to the Italian Sarcoma Group (ISG).

Andrei Ivanescu explained:

> "Exactly one year since the beginning of our collaboration with ISG, we are happy to announce that the Association EHE ITALIA has donated €17,000 to the Italian Sarcoma Group to support the research and treatment of Epithelioid Hemangioendothelioma (EHE) and other sarcomas. This gesture was only made possible thanks to the support of donors, who have demonstrated a significant commitment in the fight against these rare diseases. The association wants to express its deep gratitude to those who have contributed and invites everyone to continue supporting our mission to improve the lives of patients and promote public awareness about these cancer conditions. **THANK YOU!**"

We love to see the newest of the EHE Group foundations donating to such an important and committed group such as ISG who work tirelessly to care for sarcoma patients across Italy. ■

Ikena Oncology IK-930 granted Orphan Drug status

In late December 2023 we were excited to see that Ikena Oncology received Orphan Drug Designation from the Food and Drug Administration (FDA) of IK-930 for the treatment of epithelioid hemangioendothelioma (EHE). This is an exciting development following initial positive data from the IK-930 Phase I clinical trial that was published in November 2023. The Phase I study investigates IK-930 in patients with advanced solid tumors, including EHE.

IK-930 is one of several novel TEAD inhibitors in development, which target TEAD transcription factors that deregulate the Hippo signaling pathway in our cells. By preventing the binding to TEAD, the drugs can stop transcription of genes that drive cancer progression, metastases, and therapeutic resistance, including in EHE.

Orphan Drug Designation for IK-930 gives a strong signal that the development of the drug is on track and progressing well. Regulators, like the FDA, grant orphan drug status to incentivize companies like Ikena to continue the development of a drug for a small patient population. While there is still a long way to go, this is a positive step toward having a regulatory-approved therapy for the specific treatment of EHE.

For more information on the IK-930 clinical trial and other EHE trials, visit:

https://fightehe.org/ehe-clinical-trials/

To read more about Ikena Oncology and IK-930 you can go to these links:

- Ikena Oncology press release summarising the positive Phase 1 Trial results: https://ir.ikenaoncology.com/news-releases/news-release-details/ikena-oncology-shares-initial-positive-and-differentiated-dose
- Ikena reporting Orphan Drug Designation of IK-930: https://www.linkedin.com/posts/ikenaoncology_our-novel-tead-inhibitor-ik-930-was-granted-activity-7168620936949063681-2x4F/ (Linked In); and https://twitter.com/IkenaOncology/status/1762855331934130448 (X, previously Twitter) ■

Ablation results for EHE are published

Jane Gutkovich was the patient advocate who blazed the trail for ablation of EHE liver tumours using IRE ablation over ten years ago. IRE, together with other forms of ablation, are now widely used to treat EHE, with many EHE patients benefitting from the procedure, yet published data on ablation of hepatic EHE remains very scarce indeed. So, Jane was delighted to be able to share the news this quarter about a newly published paper. Jane said:

> **"Finally, the first study on the results of various ablations in hepatic EHE has been published. A very small study from Dana Farber, only 6 patients, but it is the first publication demonstrating that ablations are safe and overall successful."**

For those who may want to read the paper entitled 'Image-guided percutaneous ablation of hepatic epithelioid hemangioendothelioma', it was published in Abdominal Radiology on 19 January. A link to a summary can be found at:

https://link.springer.com/article/10.1007/s00261-023-04154-y

Between 2015 and 2022 the 6 patients received a total of 16 image-guided ablation procedures to treat 35 liver tumors. Different ablation techniques were used, comprising 17 microwave ablation, 9 irreversible electroporation, 8 cryoablation, and 1 radiofrequency ablation. For 4 of the 6 patients, their ablation was the first treatment received.

The results presented in this small study are indeed positive. The mean length of imaging follow-up from the first ablation procedure was 43.0 ± 31.2 months. Thirty three of 35 (94.3%) ablated tumors did not progress locally. Three patients (50%) experienced new progression in their livers and underwent repeat ablation or systemic treatment. In all 6 patients no progression of their EHE outside of their liver was observed. No severe adverse events occurred due to the ablation, but one patient sadly passed away from EHE 2.7 years after initial diagnosis.

These results are indeed positive and reflect the overall ablation experience of our global patient community. We hope to see more papers being published in the near future about the successful ablation of hepatic EHE. ■

02 EHE Research

EHE Library: Explore Recent Publications

The EHE Library is a helpful resource for patients, families, clinicians and researchers including nearly 200 articles describing EHE research, case reports, retrospective studies, and other important publications.

2024 has proven to be a productive year in EHE already, with eight (8) notable publications added to the library. Importantly, patients and advocates are working alongside expert clinicians and researchers to advance knowledge in EHE.

Visit the EHE Library to find new publications about treatments used for hepatic EHE, patients' perspectives on sirolimus, results from the Mekinist® (trametinib) clinical trial, and publications on pulmonary EHE. Links to these papers can also be found below:

- Image-guided Thermal Ablation for Hepatic Epithelioid Hemangioendothelioma: A Multicenter Experience
- A Single Arm Phase 2 Trial of Trametinib in Patients With Locally Advanced or Metastatic Epithelioid Hemangioendothelioma
- The patient perspective on sirolimus for epithelioid hemangioendothelioma (EHE): results of a community survey highlighting the importance of equitable access to treatments
- Imaging features and deep learning for prediction of pulmonary epithelioid hemangioendothelioma in CT images
- Epithelioid hemangioendothelioma (EHE) with WWTR1::TFE3 gene fusion, a novel fusion variant
- Pleural epithelioid hemangioendothelioma in a 39-Year-old female: a case report
- Image-guided percutaneous ablation of hepatic epithelioid hemangioendothelioma
- Short-term outcomes of combined therapy with sirolimus and interferon-alpha 2b for advanced hepatic epithelioid hemangioendothelioma

03 EHE Fundraising

Here you will find highlights of some of the fundraising that is the 'life blood' of the EHE Group.

Quite simply, without this ongoing fundraising none of the exciting progress reported here in The Pledge would have taken place.
We thank every single person who has organised a fundraiser of some variety, supported fundraising in any way they can, or has donated to these event.

You are all amazing!

Quiz nights are booming!

This quarter saw two great quiz nights taking place to support the EHE Rare Cancer Charity.

The first event was the second annual EHE quiz night organised by Kelly Denton and the members of Laptops and Lipstick, a women's business network based in South London. Laptops and Lipstick adopt a charity each year to support, and selected EHERCC for the 2022/2023 year. They then extended their support for a further year, holding their annual charity quiz night on 12 February at the brilliantly supportive Bridgehouse Pub in Peckham.

The event was a huge success, as Kelly explained:

> "Last year's quiz was fantastic, but this year's was even better. We again filled the pub who did an excellent job hosting the event. We also had a lot of brilliant raffle prizes. Hugh Leonard was present and gave a brief update on the research that was taking place, thanks to the generosity and support for evenings like ours. It was also special having four actual EHE patients there on the night, bringing home the reality of EHE. And to top it all, we raised £1,960 during the evening for EHE research. I was so proud of everybody who organised and participated in the event. Without them we would not have raised those critical funds."

The second quiz night was organised in mid-March by Jo and Phil Lane in support of EHE patient, Paul Dean. Jo organised a similar event in 2023 in the build up to the London Landmarks Half Marathon, and decided to do the same for the 2024 event. Jo and Phil have been wonderful supporters of Paul and the EHERCC and the three together form a formidable team.

03 EHE Fundraising

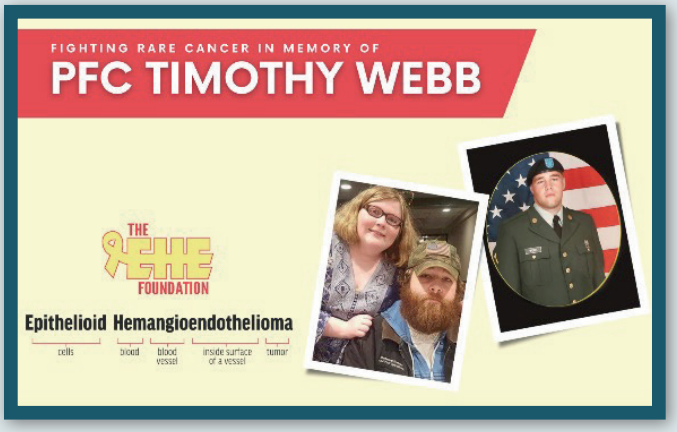
Paul Dean, EHE patient, runner and cyclist, with Jo and Phil Lane, quiz night organisers and hosts.

The Pledge want to also thank Laptops & Lipstick, Kelly, Jo and Phil for organising these lovely events, and of course all those who came along and made them so successful. ■

Raising funds in memory of a dear brother

Ellen Terpening shared news in January that Rainey Terpening was raising funds in memory of her brother, Tim Webb, who passed away in April 2019. Ellen explained:

> "Rainey's term as Worthy Advisor for The International Order of the Rainbow for Girls is almost up. Her Charity for her term is the EHE Foundation. Please help Rainey achieve her goal of reaching $400.00. Thank you so much!"



It's now her sister Lucy's turn to fundraise. Together, the girls embody a spirit of generosity and leadership as they honor their brother's memory.

It is always with great sadness that we read stories of members of our group raising funds in memory of a loved one. We are also, however, so pleased to see their memory being kept alive as friends and family continue to support our cause, determined to help find a cure for EHE. We want to thank Rainey for her commitment to help, and we are sure that Tim is looking down with a big smile, super proud of his little sister. Thank you Rainey for all that you are doing. ■

Just-Live Merch still available

Michelle Lynn posted news in February that she still had some of her lovely Just Live merchandise available, which was now being offered at reduced prices. Michelle also confirmed that she was able to ship any items to anywhere in the world!

Michelle explained that the proceeds would be going to the Wellness Retreat she is hosting. However, if purchasers wanted their purchase to go towards funding the Pro Care EHE Research Team established in Canada, then purchasers just needed to flag this in the comment section and Michelle would ensure this happens.

We wish Michelle every success with her sales and hope that the items were snapped up. ■

03 EHE Fundraising

Fitness, Awareness and Fundraising in Viterbo

On Saturday, March 16th, the Spinning Italia Tuscia My Event was held at the To Be Mattioli Fitness gym in Viterbo, with many supporters of Associazione EHE Italia - Non Solo Laura ODV attending the event. Lucia Tozzi explained:

> “For the second year in a row, EHE ITALIA was actively participating, promoting fundraising to support those who face this rare disease. These types of initiatives not only provide tangible support to the community affected by EHE, but also a message of hope and solidarity.”

For the occasion, the celebratory Tuscia My Event 2024 shirt was created! And this is not just a simple t-shirt but a shirt that could be the most intense expression of the passion, sacrifice and team spirit that went into organizing this event! If you would like one please contact Lucia Tozzi on her email at lucia.tozzi@ehe-italia.it. Andrei Ivanescu said:

> “We want to thank our Vice President Lucia Tozzi from the bottom of our hearts who took part in the event and the fundraising, presented the association, explaining who we are, what we do and our goals. We would also like to thank all the organizers of the event, particularly Riccardo Santoni who made this possible for us, all the participants and also all those who supported us from afar by purchasing t-shirts!
>
> Sport and solidarity together again... **ALONE WE ARE RARE, TOGETHER WE ARE STRONG!**” ■

Sete25bitter and Los25cycling: Solidarity Champions on Two Wheels

In early February in Savigliano in Italy, an exciting cycling race took place, thanks to the initiative of Sete25bitter and Los25cycling, a group of young cycling enthusiasts. In addition to the sporting challenge, the event has assumed a special significance as the collected donations will be donated to Associazione EHE Italia - Non Solo Laura ODV, and used in the Association's fight against Epithelioid Hemangioendothelioma. The Association said:

> "We would like to express our deep gratitude to the participants for their hard work and generosity in organising this charity initiative. Their dedication proves that sport is not just competition, but also an opportunity to do good in the community. Thank you for making such a meaningful gesture possible that will surely make a difference for those in need. We also want to say a huge thank you to the riders of Sete25bitter and Los25cycling, to Enrico Dalmasso and Elena Dalmasso for representing our Association at this event and @arsenaledelletshirt for donating the shirts."

We also want to thank all these young riders for their brilliant support for EHE. What an awesome groups of people! ■

03 EHE Fundraising

Wonderful donation from The Carlson Family Foundation

In January The EHE Foundation shared news of a wonderful donation that had resulted from one of the Foundation's posts, as they explained:

> "This is a story of social media gone right! One of our posts was shared and ended up on the feed of a board member of a small family foundation. Intrigued, they reviewed our website and liked what they saw. We were asked to apply for and then received a grant from The Carlson Family Foundation. The Carlson family has been deeply impacted by cancer, though not EHE specifically. When asked why they chose to support The EHE Foundation, they simply said, "We are all in this together."

The EHE Foundation want to sincerely thank The Carlson Family Foundation for their generosity and for understanding that we are indeed all in this together. The Pledge also wants to add its thanks for the understanding and compassion that the Carlson Family have shown. ■

Easter raffles raising research funds

People find many different ways to raise funds to support EHE research. Steph Scott and Adam Patrick will be running the London Landmarks Half Marathon in April, and have received great support on their fundraising page. But they wanted to do more and came up with the idea of holding small raffles with limited numbers of tickets through social media to raise research funds.

Their first raffle was very easter-focused, with a tantalising array of chocolates. Selling 60 tickets only at £3 each, they raised £180 for research.

Not content with this, they then launched a second raffle for a prize comprising several different spirits. We wish them success with this second raffle too, and want to thank them for such a great idea. ■

Good Vibes for McKenna III

On 20th and 21st January, Good Vibes for McKenna (GVM) held their third annual benefit concert in memory of McKenna Helm who passed away from EHE in November of 2021. Julie Wahl and LeeAnn Conner from The EHE Foundation were delighted to attend the concert and support GVM in their mission to fund EHE research. ■

Rodeo is raising bucks for EHE research!

In January The EHE Rare Cancer Foundation Australia were delighted to post news of a new sponsor down-under. M5Rodeo Promotions were also thrilled to announce their support:

> "M5Rodeo Promotions are proud to support the EHE Rare Cancer Foundation Australia with $1 from every ticket sold online donated for the M5 Beechworth Pro Rodeo. Be sure to purchase tickets to help us support such a remarkable foundation!"

Jane Biddlecombe and Jonathan Granek also wanted to thank M5Rodeo for their generosity:

> "A huge shout out to M5Rodeo Promotions for pledging a $1 donation from every online ticket sold for the 2024 M5 Beechworth Pro Rodeo to support research! The event is on 29th March and we hope as many people as possible will buy tickets."

We love to see new fundraising ideas and The Pledge is fairly certain that this is the first rodeo that we are aware of that has raised money for EHE research. Fantastic. ■

03 EHE Fundraising

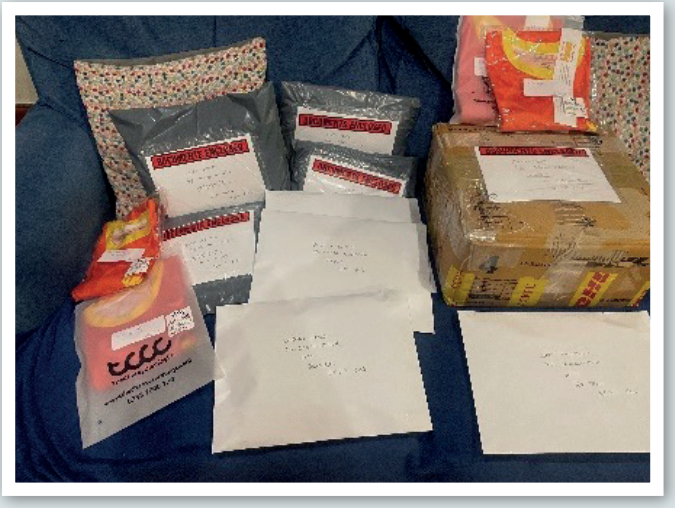
The big upcoming events...

Runners, on your marks!

As we go to print, the 2024 London Landmarks Half Marathon (LLHM) is about to take place. Sally Baker explained:

> "The London Landmarks Half Marathon will be taking place on Sunday 7th of April. This is the first of our two charity-coordinated events of the year, and is our biggest. This year we have a full team of 50 runners taking part. Most excitingly, just as we had Denise Robinson and Anne Campbell from the USA running in the team for the 2023 event, this year we have the amazing Michelle Hughes and her friend Carolyn Dohoo joining us from Canada. As always, excitement builds as the race approaches, particularly when the charity running shirts come in and we send them out to those who ordered them!"

The EHERCC has once again seen some amazing support from its UK patients and their support teams.



Paul Dean, Nicola Henderson, Alison Perry, Kim Alexander-Bird, Tracey Betts, Julie Lurie, and Sally Baker all have supporters running for them, while Steph Scott and Adam Patrick and friends were once again running in memory of the lovely Allana Parker.

Sally continued:

> "We could not be more grateful to all these 50 runners who are running for us. Many families are facing challenging financial circumstances at the moment, with inflation-driven increases in their cost of living, so we are also massively grateful to every single person who has supported us!"

We also want to echo Sally's thanks to all those who will be taking part, and send a huge welcome to Michelle and Carolyn from Canada. We hope that the 50 runners will have the runs of their lives, and of course all finish safely and without injury. **Just Run** guys; you're all awesome! ■

The EHE Foundation 2024 Fun Run and Walk is on!

We often say that EHE is a relentless adversary, and we have to be equally relentless in our response. That is why all the EHE Group foundations run annual fundraising campaigns, to continue to raise the funds to beat this rare sarcoma, and The EHE Foundation is no different. Julie Rivers Wahl was delighted therefore to announce that preparations for the 2024 Fun Run and Walk had started, and the early-bird registration was open:

> "It's that time of year! Get yourself an awesome new **Just Live shirt,** bracelet, and temporary **Just Live tattoo.** You can create a team and earn incentive prizes, walk or run by yourself or with friends, or just sign up for the EHE swag. This is an easy way to raise funds for EHE research and spread awareness for a cause so close to all of our hearts!" The charity running shirts come in and we send them out to those who ordered them! "

The EHE Foundation 2024 EHE Fun Run & Walk is a fun event for all ages and abilities. Participants choose when and where to complete their individual or team activity, and choose whether they complete 5K (3.1 miles) or 1K (0.62 miles), and complete it during EHE Awareness Month in April or at your convenience. Julie continued:

> "You can even opt to skip the run/walk altogether and spread awareness just by wearing the t-shirt! Funds raised by the EHE Fun Run and Walk support our mission of advancing research into treatments and a cure for EHE. "

There are also incentives for teams which not only encourage fundraising but also bring a lot of fun to the whole event. Teams are encouraged to tell the organisers who they're supporting so that the organisers can keep track of the teams who raise the most through donations and registrations.

03 EHE Fundraising

Team captains are also recognised for their brilliant energy and effort in creating and building a team, as Maggie Cameron explained:

> “We know you work hard rallying your supporters, so we are excited to offer these rewards to our Team Captains. These incentives build on one another, so if you reach the highest level, you get all of the rewards! Items will be mailed to Team Captains beginning in April...
>
> - **10+ Team Members**
> **$500+ in Total Dollars Raised:**
> RED TEAM CAPTAIN T-SHIRT
> (back will say TEAM CAPTAIN).
> - **25+ Team Members:**
> Drawstring bag + an extra pack of 10 tattoos and 5 bracelets.
> - **50+ Team Members:**
> RED TEAM CAPTAIN HOODIE
> (back will say TEAM CAPTAIN). ”

As always, The EHE Foundation enjoyed great response and within weeks had received over 300 registrations through the ‘Teams’ programme. Julie Whal was delighted, but also wanted to note that this was only the start:

> “Thank you to the first raft of early registrants. It’s a great start, but it is only a start.
> We desperately need to raise funds not only to drive our exciting current EHE research program but also to allow us to expand this work by committing to new areas of research that we now believe may be important to finding new treatments and a cure for EHE. So please don’t stop. Don’t think we’ve done enough. If you can join the 2024 Fun Run and Walk, and if you can encourage others to join too, we will be so grateful! And please remember that you don’t have to form a team to take part. You can also participate as individuals. Every single person who joins is critical. ” ■

Ride London Essex 100 is approaching!

Earlier in this section of The Pledge, we reported on the forthcoming London Landmarks Half Marathon, noting that this is the first EHERCC-coordinated fund raising event each year. The second such event each year is the Ride London Essex 100; a 100 mile cycling sportive which starts and finishes in Central London. Sally Baker explained:

> "This event is the largest cycling event for charities in the UK, with over 20,000 riders taking part. This year it will take place on May 26th and we have 14 brilliant riders who are signed up to ride and raise funds for EHE research. It really is physically demanding, particularly for riders who don't cycle such distances regularly. But there is also a 30 mile and a 60 mile route depending on what people feel they can do."

Hugh Leonard, Chair of Trustees of the UK Chairty will be riding again this year, his third consecutive ride in the event.

> "This may be my last ride, but as a charity, we cannot keep encouraging others to raise funds if we don't participate and take some pain ourselves. So it's time to go again." ■

04 And in other news...

We love sharing a few examples of stories which we feel amplify the group's motto - *Just Live* - even if they don't relate to one of the main activity areas of the EHE Group. We hope you enjoy them too.

Happy New Year

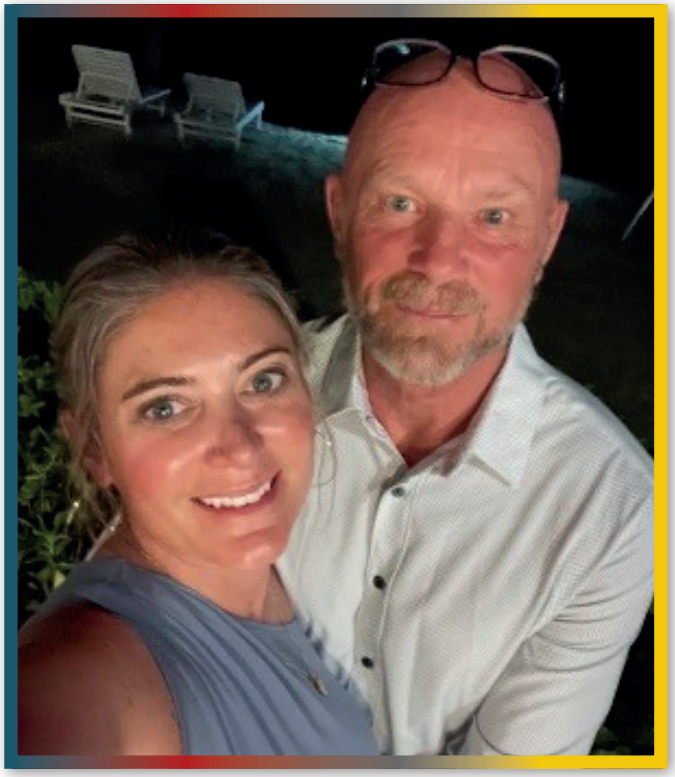
In January each year, members of our patient community post simple messages of good luck for the year ahead. 2024 was no different. Here are just two such messages and the associated photos that went with them.

Kim Delannoy reached out to the whole EHE community:

> "To my EHE family, I wanna wish you all a very good and hopeful year with lots of love and support.
>
> May you have a year, filled with love, laughter, brightness and most important **HOPE !!!**"

Carl Dickson, a regular contributor to the EHE Support page wanted to remind people to make the most of the year ahead:

> “Happy New Year my friends. Remember to create as many new memories as possible this year”



Thank you to Kim and Carl for these lovely messages. We also want to wish everybody a great 2024, and hope that you each get those things that you want most.

And always remember:

The EHE Foundation (USA)
www.fightehe.org

The EHE Rare Cancer Charity (UK)
www.ehercc.org.uk

The EHE Rare Cancer Foundation (Australia)
www.ehefoundation.com.au

EHE Italia-Associazione Non Solo Laura ODV
www.ehe-italia.it

EHE Canada
website not yet available